

**HEALTH CONDITIONS IN ADULTS WITH INTELLECTUAL DISABILITY:
 A PROPOSED SCREENING TIMELINE**

Dr Vivien Lee

ABSTRACT

There are significant health concerns faced by persons with intellectual disability (PwID) in Singapore, who experience higher rates of morbidity and mortality compared to the general population. PwID encounter various health challenges, yet despite the increased risk of chronic diseases, they are screened less. Moreover, as PwID live longer, new challenges emerge, including complications of chronic disease, and ageing-related conditions. Currently, there are no standardised guidelines for health screening for PwID, and applying regular principles of health screening to this population presents challenges. Individualised approaches are recommended based on needs, risk factors, and severity of intellectual disability. This article presents recommendations for health screening based on a Singapore charity’s experience of caring for PwID, as well as useful accommodations that might increase the success of health checkups for PwID. We also detail specific recommendations for screening of adults with Down Syndrome. Addressing the specific healthcare needs of PwID is crucial for improving their well-being and longevity.

Keywords: Persons with Intellectual Disability, Health Screening, Chronic Disease Screening, Cancer screening

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INTRODUCTION

Health Concerns among Persons with Intellectual Disability (PwID)

An estimated 1-3 percent of Singapore’s population has intellectual disability (ID).^{1,2}

Intellectual disability refers to neurodevelopmental conditions that affect functioning in two areas³:

- Cognitive functioning, such as learning, problem solving, and judgement.
- Adaptive functioning, activities of daily life such as communication skills and social participation.

DR VIVIEN LEE
 Family Physician
 Happee Hearts Movement | ID Health

Additionally, the intellectual and adaptive deficit begin early in the developmental period, typically before age 18 years for diagnosis.

PwID experience higher rates of morbidity and mortality. Mortality rates range between 2.86 to 13.15 times higher, and deaths due to causes amenable to healthcare are 7.75 times higher than general population.⁴ PwID encounter various health challenges across different domains. Prevalence of multimorbidity (two or more chronic conditions) is higher (refer to **Table 1**), and chronic diseases occur more commonly (refer to **Table 2**).

Table 1: Multimorbidity in PwID population compared to general population

	PwID Population ⁵	General Population
Multimorbidity prevalence	71.2%	58.6%
Age of onset of multimorbidity	Younger (63% in 40-49 years old)	Older
Gender distribution of multimorbidity	Females twice as likely to be multimorbid than males	Equal

Table 2: Prevalence of common medical conditions in PwID

Medical condition	Prevalence in PwID ⁵⁻¹⁰
Vision impairment	23-25%
Hearing loss	40%
Hypertension	16%
Hyperlipidaemia	18%
Diabetes	11%
Mental health disorders	40-54%
Epilepsy	21-34%
Dental disease	11-27%

In terms of sensory health, PwID are ten times more likely to experience vision impairment. Hearing impairment affects around 40 percent of PwID and is associated with Down syndrome. Sensory impairment rates are higher with increased severity of intellectual disability.

Chronic diseases including diabetes, hypertension, and hyperlipidaemia are more prevalent in PwID, attributed to a combination of genetics, sedentary lifestyles, and medication use. Despite the increased risk, PwID are often screened less frequently than national recommendations.

Mental health problems are notably higher in individuals with intellectual disabilities, with up to 54 percent reported to have such issues. Underdiagnosis is common due to the indistinct manifestation of mental health problems in this population. Risk factors include negative life experiences, social isolation, sensory impairments, and poor coping strategies.

Epilepsy is a significant concern, with PwID being 26 times more likely to develop seizures compared to the general population. The risk of sudden death due to epilepsy is higher in this group.

Dental health outcomes are poorer in PwID due to various barriers, including difficulty with dental hygiene, communication difficulties, medical complexities, and limited accessibility to dental services.

Gastrointestinal disorders, encompassing gastroesophageal reflux (GERD), *H. pylori* infection, constipation, and dysphagia are more prevalent in PwID. These conditions often lead to poor appetite, malnutrition, and, in severe cases, fatal complications like aspiration or choking.

Cancer rates are generally similar or lower in PwID. However, cancers are often diagnosed at a late stage. This is attributed to lower rates of screening and reduced access to regular healthcare.

The increased life expectancy of PwID also brings complexities. As an example, consider the journey of

individuals with Down Syndrome. In 1983, the typical life expectancy was 25 years. By 1997, it had risen to 49 years. Today, individuals with Down Syndrome can expect to live up to 60 years. This remarkable increase in life expectancy poses both opportunities and challenges. As PwID begin to live beyond the lifespan of their caregivers, new and unprecedented demands are being placed upon health and social services. In addition to their pre-existing intellectual and physical disabilities, PwID have to deal with new adult-onset or acquired conditions, chronic diseases, ageing-related conditions such as dementia and frailty, and considerations for planning of future care.

Addressing these specific healthcare needs is paramount to enhancing the overall well-being and longevity of PwID, and family physicians are well placed for this. Regular screenings, preventive measures, and inclusive healthcare practices play pivotal roles in achieving better health outcomes for this population.

SCREENING PRINCIPLES

PwID are at increased risk of multiple medical issues that can remain undetected due to interplay of client, provider, and caregiver factors.

To date, there is no gold-standard international guideline on health screening for PwID. Some countries such as US, UK, Australia, and Ireland have published local guidelines, but there are no guidelines available for Asia.

Table 3: Screening principles applied to PwID

Wilson and Jungner Screening principles of screening ¹¹	Considerations in Population of Adults with Intellectual Disabilities
The condition sought should be an important health problem	Nil
The natural history of the disease should be adequately understood	
There should be a recognisable latent or early preclinical stage	Adults with ID may have a longer detectable preclinical phase since limitations in cognitive functioning may preclude their accurately identifying and reporting symptoms
There should be a suitable and acceptable screening test or examination	Depending on the extent of cognitive impairment, screening of disease might be logistically difficult or ineffective
There should be an accepted treatment or useful intervention for patients with the disease	Depending on extent of cognitive impairment, treatment of disease might be logistically difficult or ineffective, if identified
Facilities for diagnosis and treatment should be available	Nil
There should be an agreed policy on whom to treat as patients	
The cost of case-finding (including diagnosis and treatment of patients detected) should be economically balanced in relation to possible expenditure on medical care as a whole	Depending on the different types of barriers to screening or treatment (e.g., requiring sedation/general anaesthesia, extra manpower, trauma, anxiety to patient/caregivers), the financial or psychosocial cost may be high
Case-finding should be a continuing process and not a one-off project	Nil

Not all of the principles of screening can be fully applied to PwID. As such, screening recommendations serve as decision signposts for healthcare professionals. Each patient will require an individualised approach depending on needs, risk factors, and severity of intellectual disability.

Comparison of International Screening Recommendations

Table 4: Comparison of Singapore health screening recommendations with available countries' screening recommendations for PwID

Screening	Singapore's guidelines for all adults ¹²	US recommendations for PwID ¹³	Australia recommendations for PwID ¹⁴	UK recommendations for PwID ^{15,16}	Irish recommendations for PwID ¹⁷
Obesity/Body mass Index (BMI)/Waist circumference	Yearly screening for adults aged ≥18 years	At least yearly measurement; individualised counselling (SORT B)	Yearly screening for adults aged ≥18 years	Yearly screening for individuals aged ≥14 years	Yearly screening
Hyperlipidaemia	Once every 3 years or more frequent screening above as advised by doctor for adults aged 40 years	Be alert to higher incidence of risk factors* (SORT C)	Consider screening if indicated	Consider screening if indicated	Screen adults aged >40 years if there are risk factors*
Diabetes	Once every 3 years or more frequent screening above as advised by doctor for adults aged 40 years	Be alert to higher incidence of risk factors* (SORT I)	Consider screening if indicated	Consider screening if indicated	Screen adults aged >40 years if there are risk factors*
Hypertension	Once every 2 years or more frequently as advised by your doctor for adults aged ≥18 years	Be alert to higher incidence of risk factors* (SORT C)	Yearly screening for adults aged ≥18 years	Yearly screening for individuals aged ≥14 years	Yearly screening
Colon cancer	Faecal Immunochemical test (FIT) yearly OR colonoscopy once every 5-10 years for adults aged ≥50 years	FIT yearly or colonoscopy every 10 years for adults aged 45-75 years old; may combine with other tests while patient is under sedation (SORT B)	Faecal occult blood test (FOBT) every 2 years for adults aged ≥50 years	FIT every 2 years for adults aged 60-75 years old	FIT every 2 years for adults aged 55-74 years old
Breast cancer (women)	Mammogram once every year for women aged 40-49 years old, every 2 years for women aged 50-69 years old	Mammogram every 1-2 years for women aged 40-74 years old (SORT C)	Mammogram one every 2 years for women aged ≥50 years	Mammogram once every 3 years for women aged 50-71 years old	Mammogram once every 3 years for women aged 50-69 years old

Cervical cancer (women)	Pap test (for 25-29 years old) every 3 years. Human Papillomavirus (HPV) test (for ≥30 years) once every 5 years	Pap smear (for 21-29 years old) every 3 years. HPV test (for 30-65 years old) Individualised to patient's risk factors (generally can be done less often) (SORT B)	HPV test once every 5 years for women aged 25 years	HPV test once every 3 years for women aged 25-49 years old; once every 5 years for women aged 50-64 years old	HPV test once every 3 years for women aged 25-29 years old; once every 5 years for women aged 30-65 years old
Skin cancer	Insufficient evidence to recommend	Insufficient evidence to recommend (SORT I)	Skin check yearly for adults aged ≥18 years	Skin check yearly for individuals aged ≥14 years	Consider condition of skin yearly
Osteoporosis	Bone marrow density (BMD) for post-menopausal women aged ≥65 years, men aged ≥70 years	Yearly screening for adults aged >40 for institutionalised patients and aged >45 for community-dwelling patients, especially with risk factors** (SORT B)	Consider vitamin D screening. Be alert for risk factors** and screen as needed	Vitamin D screening if on anti-epileptic drugs. Be alert for risk factors**	Yearly assessment for risks factors**
Vision and hearing	Insufficient evidence to recommend	At least yearly; modified/individualised methods (SORT B)	Yearly screening for adults aged ≥18 years	Screen vision for individuals aged ≥14 years every 2 years. Screen hearing every 3 years for adults aged ≥40 years, or at any age if has Down Syndrome	Yearly screening for vision. Consider hearing issues yearly. Formal hearing screen for individuals with Down Syndrome every 3 years
Mental health	Insufficient evidence to recommend	Yearly with attention to physical symptoms of mood disorders (SORT C)	Yearly screening for adults aged ≥18	Yearly screening for individuals aged ≥14 years	Yearly screening
Dental	At least 6-monthly review for adults aged ≥18 years	-	6-monthly review for adults aged ≥18 years	Yearly review for individuals aged >14 years	Yearly review with dentist. 6-monthly review with dental hygienist
Podiatry	Insufficient evidence to recommend for general population. Diabetic foot screening annually for adults with diabetes mellitus	-	-	Consider condition of feet yearly for individuals aged >14 years	Consider condition of feet yearly

**Risk factors for CAD that would prompt earlier lipid measurement: hypertension, obesity, inactivity, family history of CAD, known diabetes or lipid disorder, cigarette smoking, medications (anti-psychotics)*

***Risk factors for osteoporosis that would prompt earlier and more frequent screening: cerebral palsy with immobility, previous fractures, hypogonadism or premature ovarian failure, autoimmune diseases (rheumatoid arthritis, type 1 diabetes mellitus), hyperthyroidism, hyperparathyroidism, vitamin D insufficiency, chronic malnutrition, malabsorption, chronic liver disease, alcohol use, cigarette smoking, medications (steroids, proton pump inhibitors, thiazide diuretics, thiazolidinediones, anti-epileptics, medroxyprogesterone acetate, selective serotonin receptor inhibitors), loss in height. A lost in height of >5 cm is an important sign of an asymptomatic vertebral compression fracture.*

SORT = Strength-of-Recommendation Taxonomy¹⁸

Strength of recommendation	Definition
A	Recommendation based on consistent and good quality patient-oriented evidence
B	Recommendation based on inconsistent or limited-quality patient-oriented evidence
C	Recommendation based on consensus, usual practice, opinion, disease-orientated evidence, or case series for studies of diagnosis, treatment, prevention, or screening

Screening for Adults with Down Syndrome

Additionally, adults with Down syndrome have common associated medical conditions that will require regular screening.

Table 5: Screening recommendations for adults with Down Syndrome¹⁹

Screening	Recommendations for adults with Down Syndrome
Dementia	Medical professionals should assess adults with Down syndrome and interview their primary caregivers about changes from baseline function annually beginning at age 40
Atlantoaxial instability	Annual screening for adults with Down syndrome should be based on a review of signs and symptoms of cervical myelopathy using targeted history and physical exam
Thyroid	Annual screening for hypothyroidism should be performed

Practical Tips for Busy Primary Care Physicians

In a busy primary care clinic, it may be difficult to practically attend to all the health screening needs for PwID. We recommend prioritising the following screenings detailed in **Table 6**. If there is more time and resources or in the presence of strong risk factors, the other screenings including osteoporosis, mental health, vision, hearing, cancer, podiatry and dental should be considered.

Table 6: Health Screening priorities

Screening	Recommendations
Obesity (BMI)	Yearly screening for adults aged ≥ 18 years
Hyperlipidaemia	Once every 3 years or more frequent/earlier screening if there are risk factors for adults aged 40 years
Diabetes	Once every 3 years or more frequent/earlier screening if there are risk factors for adults aged 40 years
Hypertension	Once every 2 years for adults aged ≥ 18 years
Thyroid disorders	Annual screening for adults with Down Syndrome

Accommodations

PwID may have difficulties understanding the need for health screening and how the screening will be done. Procedures that are commonplace to us like blood pressure taking or blood taking can be terrifying for them. There are some tips which we have found to be helpful to increase the chances of a successful health check-up. Refer to **Table 7**:

Table 7: Tips to increase the success of health checkup

Train	Do preparation prior to planned health checkup. This can involve Easy Read materials (materials that are easier to understand), social stories, visual aids, or videos to prepare the PwID for the steps involved in a health checkup. This will help to alleviate any anxiety or fear caused by a sudden health checkup.
Time	Sufficient time and a comfortable space will ease the PwID for health checkups. Consider arranging appointments when the clinic is less crowded and busy.
Trust	Rapport and continuity of care is important. As the PwID gets more comfortable with you and the clinic staff and trusts you, he/she will tend to allow the healthcare team to perform various examinations and procedures on himself/herself.
Try and try again	Do not give up! Schedule PwID for return visits to re-attempt screening. Each visit increases familiarity. PwID have many undiagnosed health needs and will need your care and patience to optimise their health outcomes.

Local resources such as Easy Read materials, visual aids, and videos can be accessed from our website (<https://happee hearts.com/resources/>). There are also overseas resources available online.

Where screening cannot be performed due to refusal, it can be helpful to get support from IDHealth to support the individual through the procedures. IDHealth also has a network of partners (e.g., optometrists, dentists etc.) who can help to support the various screenings.

In cases where multiple attempts were made to no avail, it is best to coordinate with a healthcare team who may be doing a procedure under sedation or general anaesthesia and do all the necessary health screening at the same time.

After the Screening: Abnormal Results

Any abnormal screening results can be followed up as per the general population. If additional support is needed to guide the patient and family through further investigations or procedures, you may contact IDHealth team for further consultation and support.

CONCLUSION

PwID have increased risks of multiple health issues that are often undetected due to compounded barriers to healthcare services. Consequently, they have increased mortality and morbidity at a younger age compared to general population. Although there are no formal local guidelines for health screening in this population, it is of utmost importance to

pay attention to preventive health screening to optimise their health outcomes.

REFERENCES

1. Department of Statistics Singapore. Singapore Census of Population 2020 [Internet]. 2020 [cited 2024 Jul 1]. Available from: <http://www.singstat.gov.sg/publications/reference/cop2020/cop2020-sr1>
2. Ministry of Social and Family Development. Total Number of Persons with Disabilities in Singapore. [Internet]. 2018 [cited 2024 Jul 1]. Available from: <https://www.msf.gov.sg/media-room/article>
3. American Psychiatric Association. Arlington, VA APA Publishing. Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition-Text Revision. [Internet]. 2022 [cited 2024 Jul 1]. Available from: <https://www.psychiatry.org/443/psychiatrists/practice/dsm>
4. Reppermund S, Walker AR. Addressing the High Rates of Mortality in People With Intellectual Disability. *JAMA Netw Open*. 2021 Jun 1;4(6):e2113446.
5. McCarron M, Swinburne J, Burke E, McGlinchey E, Carroll R, McCallion P. Patterns of multimorbidity in an older population of persons with an intellectual disability: results from the intellectual disability supplement to the Irish longitudinal study on aging (IDS-TILDA). *Res Dev Disabil*. 2013 Jan;34(1):521–7.
6. Hardy S, Chaplin E, Woodward P. Supporting the Physical Health Needs of People with Learning Disabilities: A handbook for professionals, support staff and families. Pavilion Publishing and Media Ltd; 2016. 250 p.
7. Wee LE, Koh GC, Auyong LS, Cheong AL, Myo TT, Lin J, et al. The medical, functional and social challenges faced by older adults with intellectual disability. *Ann Acad Med Singap*. 2013 Jul;42(7):338–49.
8. Rai D, Stansfeld S, Weich S, Stewart R, McBride O, Brugha T, et al. Comorbidity in mental and physical illness. Mental health and wellbeing in England: Adult Psychiatric Morbidity Survey Chapter 13 Leeds: NHS Digital. 2016;
9. Cooper SA, McLean G, Guthrie B, McConnachie A, Mercer S, Sullivan F, et al. Multiple physical and mental health comorbidity in adults with intellectual disabilities: population-based cross-sectional analysis. *BMC Family Practice*. 2015 Aug 27;16(1):110.
10. Teo CHK, Mahesh MN, Lim GXD. Oral health status and barriers to care in a multiethnic mixed disability center: Rethinking disability community dental services. *Spec Care Dentist*. 2020 Jul;40(4):344–55.
11. Wilson JMG, Jungner G, Organization WH. Principles and practice of screening for disease. 1968 [cited 2024 Jul 1]; Available from: <https://iris.who.int/handle/10665/37650>
12. Health Hub. Evidence-based Recommendations on Health Screening Tests [Internet]. 2023 [cited 2024 Jul 1]. Available from: <https://www.healthhub.sg/live-healthy/type-2-screening-tests>
13. Wilkinson JE, Culpepper L, Cerreto M. Screening tests for adults with intellectual disabilities. *J Am Board Fam Med*. 2007;20(4):399–407.
14. Centre for Developmental Disability Studies, University of New South Wales. Health care in people with intellectual disability: Guidelines for general practitioners. 2006.
15. National Health System, United Kingdom. A summary and overview of the Learning Disability Annual Health Check electronic clinical template [Internet]. 2017 [cited 2024 Jul 1]. Available from: <https://www.england.nhs.uk/wp-content/uploads/2017/05/nat-elec-health-check-ld-clinical-template.pdf>
16. M Kerr, RG Jones, M Hoghton, H Houston, J Perry, AK Thapar, et al. National Centre for Mental Health. [cited 2024 Jul 1]. Learning Disability health check forms. Available from: <https://www.ncmh.info/resources/online-tools/learning-disability-health-check-forms/>
17. Trinity College Dublin. Health Check [Internet]. 2019 [cited 2024 Jul 1]. Available from: <https://www.tcd.ie/tcaid/assets/pdf/HSEHealthCheck.pdf>
18. Ebell MH, Siwek J, Weiss BD, Woolf SH, Susman J, Ewigman B, et al. Strength of recommendation taxonomy (SORT): a patient-centered approach to grading evidence in the medical literature. *J Am Board Fam Pract*. 2004;17(1):59–67.
19. Tsou AY, Bulova P, Capone G, Chicoine B, Gelaro B, Harville TO, et al. Medical Care of Adults With Down Syndrome: A Clinical Guideline. *JAMA*. 2020 Oct 20;324(15):1543–56.

LEARNING POINTS

- **Persons with intellectual disability have poorer health and lower access to healthcare services than the general population.**
- **There are no standardised guidelines for health screening for adults with intellectual disabilities. There is a need for the development of local health screening guidelines for this population.**
- **Individualised health screening is important and should be done with accommodations as required.**